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### Dangling Conversations

**Citation for published version:**

Stenhouse, R., Tait, J., Hardy, P. & Sumner, T. 2013, 'Dangling Conversations: Reflections on the Process of Creating Digital Stories During a Workshop with People with Early Stage Dementia', *Journal of Psychiatric and Mental Health Nursing*, vol. 20, no. 2, pp. 134-141. <https://doi.org/10.1111/j.1365-2850.2012.01900.x>

**Digital Object Identifier (DOI):**

[10.1111/j.1365-2850.2012.01900.x](https://doi.org/10.1111/j.1365-2850.2012.01900.x)

**Link:**

[Link to publication record in Edinburgh Research Explorer](#)

**Document Version:**

Peer reviewed version

**Published In:**

Journal of Psychiatric and Mental Health Nursing

**Publisher Rights Statement:**

© Stenhouse, R., Tait, J., Hardy, P., & Sumner, T. (2013). Dangling Conversations: Reflections on the process of creating digital stories during a workshop with people with early stage dementia. *Journal of Psychiatric and Mental Health Nursing*, 20(2), 134-141. 10.1111/j.1365-2850.2012.01900.x

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**Dangling Conversations: Reflections on the process of creating digital stories during a workshop with people with early stage dementia**

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**Acknowledgements**

This work was funded by the generous gift of an Alumnus of the University of Abertay Dundee.

**ABSTRACT**

Care and compassion are key features of the NHS Constitution. Recent reports have identified a lack of compassion in the care and treatment of older people. Nurses draw on aesthetic knowledge, developed through engagement with the experience of

others, when providing compassionate care. Patient Voices Reflective digital stories are used in healthcare education to facilitate student engagement with the patient experience. Digital stories were made with seven people with early stage dementia as part of a learning package for student nurses. In this paper the authors reflect on their experience and observations from facilitating the four day digital story making workshop. Social theories of dementia provide a theoretical framework for understanding these reflections. Despite considerable challenges in developing a story, and anxiety about using the technology, reading and speaking, all participants engaged in creating their own digital stories. Positive changes in the participants' interactions were observed. These improvements appeared to be the product of the person-centred facilitation and the creative process which supported self-expression and a sense of identity. Nurses working in this way could facilitate the person with dementia's ability to participate in their care, and improve their sense of well being by supporting self expression.

**Key words:** Dementia care; digital stories; creativity; interpersonal relationships; user involvement

**Accessible summary:**

- Digital stories provide a creative way for people to tell their stories using an amalgamation of voice, image and music, and can be used to engage nurses with others' experiences in the classroom setting.

## Creating digital stories with people with dementia

- Seven people with early stage dementia and one carer participated in making their own stories during a digital storytelling workshop.
- These participants experienced particular and varied challenges relating to telling a story and engaging with the technical process of digital storytelling.
- Participants were supported in overcoming these challenges through person-centred relationships with facilitators, allowing them to negotiate the help required.
- During the workshop a number of positive changes were observed in the participants: increased confidence; improved speech; a sense of purpose; and increased connection.

## INTRODUCTION

The NHS Constitution identifies compassion as one of its underpinning values (DH, 2010). However, recent reports have highlighted a lack of compassion in the care of older people in a range of hospitals within the NHS (Abraham, 2011; Mental Welfare Commission for Scotland, 2011). Within mental health nursing, the value of compassion as a nursing attribute is reflected in the move toward values-based nursing (Scottish Executive, 2006; DH, 2006), and through the Nursing and Midwifery Council (NMC) standards for pre-registration for nursing (NMC, 2010).

The nurse's capacity to provide compassionate care may be linked to Carper's (1978) notion of aesthetic knowledge (Holtslander, 2008; Haigh & Hardy, 2010). In her seminal article, Carper (1978) identified four *fundamental patterns of knowing in nursing* (Holtslander, 2008: 25): empirical, aesthetic, personal knowledge and ethics. Aesthetic ways of knowing involve understanding the human experience, and are integral to the nurse's capacity to care for the patient (Holtslander, 2008; Hunter, 2002). This form of knowledge is developed through emotional engagement with the experiences of others (Hunter, 2002; Benner, 1984; Kidd & Tusai, 2004; Kendall & Murray, 2005). Whilst in the clinical environment this occurs as nurses interact with patients and families (Benner, 1984), in the academic environment alternative means of facilitating interaction with others' experience must be found.

The arts – stories, digital stories, drama, and poetry - have been used to bring patients' experiences into the classroom (Grindle & Dallat, 2001; Schwartz & Abbott, 2007; Hardy, 2007; Stacey and Hardy, 2010). Through art experience is represented, inviting the audience to take notice of the ordinary by presenting it in an alternative form (Barone & Eisner, 2011; Shklovsky, 1965). Such 'taking notice' requires the audience to engage with the artist's representation during the interpretive process (Shklovsky, 1965; Barone & Eisner, 2011; Finley, 2008). Thus, the use of art to represent patient experience has been found to increase engagement and understanding, and is perceived to facilitate the development of aesthetic knowledge (Hunter, 2002; Grindle & Dallat, 2001; Schwartz & Abbott, 2007).

Digital stories are an arts-based method of representing patient experience. Using voice, image and music, people represent their experience in three to five minute films. When watched by nurses, Patient Voices Reflective Digital Stories have been found to have an impact on emotions and facilitate the development of empathy (Haigh & Hardy, 2010).

A project to develop a learning package aimed at helping undergraduate nurses engage with the experiences of people with dementia identified digital stories as a suitable medium for this. Key to developing the learning package was a four day digital storytelling workshop where seven people with early stage dementia and one carer made digital stories.

In this paper the authors reflect on the process of making digital stories during this workshop, drawing on social theories of dementia to understand these reflections and identify clinical relevance.

### **Dementia and creativity**

Social models of dementia focus on the socially constructed nature of ‘self’ or ‘personhood’ (Kelly, 2010; Kitwood, 1997; Small et al, 1998), through the interplay between biological, social and psychological aspects of the person. Kitwood (1997) described a dialectical relationship between neurological changes and negative social interaction which could lead to depersonalisation of the person with dementia. He identified seventeen aspects of negative social interaction. However, he also identified ten elements of positive social interaction, including recognition, collaboration, validation, creation, and giving proposing that caregivers develop an interactional style based on these to support personhood.

Sabat and Harre (Small et al, 1998; Kelly, 2010) argue for the continued existence of self in people with dementia despite cognitive decline. Their observation of interactions between four people with dementia and their caregivers forms the basis of the selfs framework (Kelly, 2010), a conceptual framework identifying three levels of self (Selfs 1-3). The differentiation of these Selfs relates to the level of social interaction implicated in the formation of self-identity with a range of lexical markers. Self 1 refers to a sense of self as a differentiated, bounded person, evidenced by the use of ‘I’, ‘mine’ or ‘me’. This is questioned by Small et al. (1998) who found that

participants who did not use first person pronouns demonstrated a sense of self through resistance and conflict, defending their rights. Self 2 is the level at which the individual draws on their understanding of, and beliefs about, their personal characteristics. This is expressed as ‘I am good at baking’, or ‘I am not good at singing’. Kelly (2010) suggests that Self 2 can be influenced by positive affirming, or negative interactions. Self 3 refers to the relational aspects of identity; how others perceive the person with dementia, leading to a particular interactional style and role designation (Kelly, 2010).

This theoretical perspective suggests that self or personhood (for clarity these will be referred to as self except when explicitly referring to Kitwood’s (1997) concept of personhood) is constituted and maintained through social interaction. Interactional styles, therefore, have the potential to support or deny self-expression (Kelly, 2010; Small et al, 1998). The biggest threat to self is, therefore, not the progressive neurological decline of dementia, but the perception and behaviour of others towards the person (Bond & Corner, 2001; Kelly, 2010; Kitwood, 1997).

Self-identity may be supported through creative activity, offering the opportunity for self-expression (Kelly, 2020; Peisah et al, 2011). Peisah et al (2011) documented the improvement in well-being observed in a patient with severe dementia who participated in art therapy. Aadlandsvik (2008: 335) detected a “*slight therapeutic effect*” when creating poetry with a small group of people with early stage dementia.. It is difficult to ascertain whether these improvements were linked to the activity or the form of social interaction between the person with dementia and the professional



during the sessions. Indeed, unlike the study which they replicated, Gigliotti et al (2004) found no difference in effect between participants with dementia who participated in horticultural therapy activities and usual day service activities, attributing this to the person-centred approach being offered by the day service.

Kelly (2010) identified a link between the increased well-being scores of people who took part in Occupational Therapy (OT) sessions and the person-centred relationship developed with the OTs. This relationship was qualitatively different to that formed with nurses (Kelly, 2010). Rhynas (2010) identified the task-oriented focus of nursing activities, based on the notions of forgetting and decline. Her findings highlight the domination of a medical model, and perhaps offer an explanation for the impoverished state of research literature examining the use of creative activities with people with dementia.

### **Digital storytelling methodology**

Digital storytelling is a generic term used to describe the use of new media technologies to create innovative narrative forms. Still images, usually drawn from the storyteller's personal photograph albums, are combined with a recorded voiceover, scripted by the storyteller, and sometimes music is added. In reflective digital storytelling, this results in a rich tapestry that is at once 'Effective, Affective and Reflective' (Hardy and Sumner, 2010). The process is person-centred, with participants retaining control over the story that is told. O'Neill and Hardy (2008)

identified that, within the context of the workshop, storytellers experienced a stronger feeling of shared humanity.

## **THE DIGITAL STORYTELLING WORKSHOP**

### **The facilitators**

Prior to the recruitment of participants, RS participated in a digital storytelling workshop with the Patient Voices Programme (PVP) to experience their reflective digital storytelling process as a storyteller, and gain understanding of how it might be used with people with dementia. JT had participated in several digital storytelling workshops with the PVP as both a storyteller and a facilitator. PH and TS are experienced facilitators of reflective digital storytelling workshops within the PVP.

### **Participants**

Originally eight people with early stage dementia had indicated that they would like to participate. However, one person decided that they did not wish to do so. Seven people with different forms of dementia, and a variety of cognitive and functional difficulties, participated in the workshop. These participants were all part of an early stage dementia group in a local dementia centre. The paid carer who runs the group also participated in the workshop. RS met with the group on several occasions prior to the workshop to get to know them and understand how best to design the workshop so that participants needs were met.

Two facilitators visited a month prior to the workshop to show some digital stories and explain the Patient Voices digital storytelling process. Group members were all invited to tell a short story about their names to get a sense of how the storytelling process might work in practice. Carers were also invited to this as it formed a key information-giving session in relation to consent.

### **The workshop**

The workshop took place over four consecutive days, with four participants attending in the morning and four in the afternoon. This enabled the facilitators to work with them on an individual basis, and ensured that they would not become exhausted or disengaged from the process. The main tasks of each day are shown in box 1.

### **Evaluation of the workshop**

Participants had consented to photographs being taken during the workshop as a means of evaluating their engagement. At the end of day four, the group were asked to comment on their experience of the workshop.

### **Facilitator reflective sessions**

The four facilitators met at the end of each day to reflect. During the workshop facilitators were fully engaged in interaction with the participants, and their experience of these interactions and informal observations formed the basis of these reflective discussions. None of the authors had previously facilitated a digital storytelling workshop with people with dementia, so these discussions were intended to facilitate the adaptive process of the workshop. However, it became clear that the reflections were about interpersonal relationships and theoretical understandings of these, particularly in relation to narrative and storytelling. The reflections were

recorded and notes taken. The content of the reflective sessions was organised thematically. Three themes emerged: engaging with story; engaging with doing; and engaging with others. These are presented below, supported by quotations from these reflective sessions.

### **Ethical issues**

Ethical approval for the project was gained from the University of Abertay Dundee's research ethics committee.

A person-centred, process approach to consent was adopted (Dewing, 2007; Sheratt *et al*, 2007). The PVP's three-stage, informed consent and release procedure was followed throughout the process (Hardy and Sumner, 2010). Participation was voluntary. Written information about making digital stories and their use for teaching nurses/student nurses was given out to carers, group members and staff. Carers were involved in the information-giving process so that they could support informed consent (Alzheimer Scotland, 2000). Care staff were fully informed so that they could help group members decide whether to participate. The issue of consent was treated as an integral part of the relationship between facilitators and participants (Dewing, 2007; Innes, 2009; Hollway & Jefferson, 2000; Hardy and Sumner, 2010). Written consent was given by all participants.

### **REFLECTIONS ON THE PROCESS OF MAKING DIGITAL STORIES DURING THE WORKSHOP**

The participants with dementia participated in all aspects of making their digital stories. There were risks in undertaking this process: facilitators and participants were uncertain about what to expect. Participation was facilitated through relationship and negotiation. This section reflects on participants' engagement with different elements of the workshop.

### **Engaging with story**

The participants with dementia experienced a variety of difficulties in constructing a narrative. Generally this related to the ability to hold onto the threads of a story. One participant in particular experienced a form of word association so that when she used particular words in her story these triggered other stories.

*... there isn't that sense ... of the point of the story. ... There were several points, kind of a spiral, but never quite completing the circle.*

Day 1

*If you never get to the end, how do you know what the story is? There is never a sense of completion and, as they talk about each thing, the point of the story changes as you change the focus of the story.*

Day 1

Other people told fragments of unconnected stories.

*So what sometimes seems as though it's turning into a narrative is actually a coincidental alignment of different bits.*

Day 1

One person had severe difficulties in finding the words necessary to express himself.

*[P1] told me that his story was about the difficulty in being able to communicate today. So I suppose my input was more to help him develop the context in which other people could understand the story. So we just sat and talked – I wanted to use his words. But he had given me that key.*

Day 1

In this way, facilitators used active listening and reflection skills to gain greater understanding and make connections between the different stories that participants told.

*I feel I should have been more prescriptive with [P3] – I may have to be more guiding, because I don't think the ability to synthesise is still there.*

Day 1

*I asked [P5] – she has lots of reminiscences about her family – why are they important? Really hard for her to say. Eventually I took the bull by the horns. What would you like people to think about when they hear your story? She pretty quickly said, 'I'm a really positive person. I try to make the best of things.' Then it became pretty easy to start by 'I have a really good long term memory'. And then it ended with 'my mother and my grandmother always make the best of things.' And she liked it when I read it back to her.*

Day 1

Photographs that they had brought with them were used as prompts to help develop their stories.

*Storytellers were quite engaged with getting more pictures. [P3] went out and took photos of the graveyard where her mum is buried and [P5] found a photo of himself at age 4.*

Day 4

*They could see the benefit and they wanted to do it. They've used their initiative because it matters to them.*

Day 3

Throughout this process facilitators were working with individuals, trying to gain a sense of what the important stories might be, holding the threads and making space for stories to develop.

Participants displayed insights into the impact of their dementia on themselves and their relationships with the social world. Many of the stories identified issues of loss, yet the form of narrative was matter of fact:

*With [P3], I've said 'how has that been affected by your diagnosis? Is having to stop driving an issue for you? ... [losing the cars she loved to drive, a successful business] didn't seem to have an emotional connection with her.*

Day 1

Only one participant seemed to have any emotional connection to his story.

*[P6] is the only one with an emotional connection to his story – so he has to keep stopping because it's too much for him to cope with emotionally.*

*He is at an earlier stage than most of the others, so perhaps he still has an emotional connection that's lost as the dementia continues. So there is something about emotion and the story – does emotion give the story coherence? Maybe that's the glue that holds the story together.*

Day 3

Participants also told stories of practical coping strategies, their concerns about the welfare of their carers, and their attempts to retain independence.

During the story circle on the second day of the workshop participants were supported to read their scripts to the rest of the group. Many participants were reticent about this, as reading had become problematic. However, only one participant chose not to read

his script. The reading of the scripts prompted discussion about the stories, and group members were supportive of each other, laughing at funny stories, and displaying warmth and mutual support during one story where the storyteller was visibly emotional.

The level of engagement with stories increased as the workshop progressed. Initially, and unusually, the participants did not respond to the showing of exemplar Patient Voices digital stories either at the induction meeting or at the beginning of the workshop.

*I thought it was really good when you [PH] showed your own digital story [at beginning of day 3]. I noticed [P7] was really engaged with it. Was that because he's been through the process?*

Day 3

When we showed the participants their own stories on the big screen at the end of the workshop, all engaged with these. This was evidenced by their focus on the screen, and the verbal and non-verbal responses to the stories. The photographs taken throughout the workshop show the participants to be actively engaged in the process.

### **Engaging with 'doing'**

#### *Reading and recording the voiceovers*

Having co-constructed the story scripts with the facilitators, participants were required to record these as the soundtrack for their digital story. Initially, only one person expressed confidence about reading their script. Others demonstrated difficulties in relation to following a sentence, partial sight, and the inability to articulate the words. All scripts were printed in a large, clear font.



However, several participants found that their eyes strayed down across the page so that they could not easily follow and read a sentence. The facilitators adopted a variety of methods of presenting the scripts, designed to make the reading of the scripts by the storytellers as easy as possible. One storyteller had read the script fluently the day before, but on the day of recording, appeared anxious and unable to follow the lines. The script was amended so that it was in larger font with one sentence per line, and then cut into strips of paper, enabling her to read her story.

*We need to stop at least every ten lines to allow her to breathe.*

### Day 3

Facilitators encouraged people to practice reading the scripts out loud. One person had experienced ongoing difficulties finding the words to express himself, resulting in a loss of confidence and reduction in verbal interaction over the course of his dementia. This created a lot of anxiety when required to tell his story. The facilitator encouraged him to read slowly, taking care to offer the time for him to do so and not feel rushed, practising until he felt confident enough to be recorded.

### *Using the technology*

The storytellers were shown how their story would be assembled using video editing software, in an attempt to engage them with the process. Participants had expressed early anxiety about using laptops, however, their role evolved into that of *director*, whilst the facilitators *drove* the computer. Participants listened to the recording of

their stories with the facilitator who helped them place the pictures they had chosen against the relevant part of their voiceover

Relating scanned, onscreen images to the physical photographs was challenging for some. A contact sheet was printed to help them see the range of images available to choose from.

### **Engaging with others**

The participants were a ready formed group prior to the workshop, and therefore had established patterns of interaction. During the workshop they were observed to be supportive of each other, and sensitive to the emotional challenges experienced by one group member during participation. The sense of engagement with each others' stories was particularly strong during the *premiere* on the fourth day.

*They watched with much more interest than when they watched the example stories, and responded better*

Day 4

*... they were quite emotionally impacted –[P5] and her friend definitely were. She was obviously struggling to keep control of her emotions - she didn't want to cry.*

Day 4

During the workshop, it was noted that the participant who had initially demonstrated the most extreme difficulties with his speech became increasingly confident in his ability to express himself. This observation was supported by comments from his wife who stated that she could not get him to stop talking on the evening of the second day,

and similar observations by care staff. The participant himself made several comments about how he felt he was improving; *"I'm on second level today"*, connecting this to the support he was getting from his facilitator. Group members recognised and acknowledged his increased confidence and verbal interaction.

Following the *'premiere'* of the completed stories on day four, participants expressed a sense of individual and group achievement that was clearly visible to facilitators and staff. This instigated discussion amongst the group of a wider premiere of the stories to an invited audience. This premiere was held two months later in a small cinema, and approximately 50 guests attended including families, carers, a consultant psychiatrist and variety of mental health workers. All the storytellers were present and, by their own accounts, felt acknowledged by the audience's appreciation for their stories. One remarked that *"it is good to be known"* and another visibly glowed when a man in a suit sat down beside her, saying, *"so you used to be a solicitor?"*

## **DISCUSSION**

This workshop demonstrated that people with early stage dementia are able to participate in creative activities involving technology and story telling. Engagement with these activities is supported by the development of facilitative relationships. It would appear that involvement in the workshop had benefits for participants' sense of self.

The finding that participation in the workshop engendered some improvement in the participants' social interactions is supported by the findings of other studies (Kelly, 2010; Peisah et al, 2011; Aadlandsvik, 2008). Common to each is participation in creative activity within the context of a relationship which supported the self. The focus on self-expression during digital storytelling led to the development of relationships which supported self through "*positive person work*" (Kitwood, 1997: 89); recognition, negotiation, collaboration, play, stimulation, holding, celebration, validation, facilitation, creation and giving.

The process of enabling the participants to find and tell their story had the potential to affirm or deny self. The facilitator had to take responsibility for holding the threads of the emerging story whilst supporting self-expression. Wiersma (2011) describes how the involvement of carers in her project where people with dementia took photographs as a means of documenting their lives had the potential to close down self expression through controlling or critical interaction. During the workshop the facilitators worked collaboratively with the participants, mindful of their influence on the story told.

Participation in a new process was also challenging and several participants voiced concerns that they no longer possessed particular skills required for the project. The task of reading their scripts aloud raised particular concern. However, all recorded voiceovers. This was achieved through the relationship where time, encouragement and practical adaptations facilitated engagement, supporting Kelly's (2010) argument that positive social interaction may influence elements of self 2 relating to the

person's perception of their current skill level. Resonating with the findings of Aadlandsvik (2008) and Savundranayagam et al (2011), the creation of a product may engender a sense of achievement, which further maintains or develops self

Storytelling occurs in the context of social relations with an audience (Riessman, 2008). Within the workshop the audience was present in the form of the facilitators and other participants. However, the digital stories were created for use in nurse education, connecting the participants with a wider audience. Having their stories attended to within the context of these relationships may lead to affirmation of self and a sense of community (Peisah et al, 2011; Savundranayagam et al, 2011).

Comments following the Premiere indicate that participants experienced a sense of connection to a wider community. Similarly, Savundranayagam et al (2011) identified the self-affirming experience of participation in life story interviews which were recorded for family and friends.

The creation of products such as digital stories, poems (Aadlandsvik, 2008), or life story interviews (Savundranayagam et al, 2011) may support self not only through a sense of achievement, but through the expression of self. These arts-based forms of self expression can engage the audience in a way which encourages deeper knowledge of the experience of dementia (Aadlandsvik, 2008; Hunter, 2002; Grindle & Dallat, 2001; Schwartz & Abbott, 2007). This changes the participant's relationship with the audience, potentially supporting the development of Self 3 as perceptions of people with dementia change.

Increasingly within the health services, education and research, service user involvement is promoted as a means to improving the quality of care. Issues of capacity and consent can lead to the exclusion of people with dementia from participation in research (Sherratt et al. 2007) and reinforces the stereotypes of people with dementia as incapable (Wiersma, 2011). The creation of digital stories by the participants as part of a learning package is evidence that people with dementia are able to contribute and engage with a wider audience.

### **Conclusions**

The workshop demonstrated that people with early stage dementia have the capacity to engage with digital storytelling. Reflection on the process of this workshop highlights the relationship between participant and facilitator as a key element. These relationships promoted positive person work, enabling participants to develop their stories, creating a safe space where they overcame the challenges of finding the words and holding onto the thread of the story, reading out loud and interacting with computer-based technology. Whilst no formal measures were used, it seems reasonable to suggest that there was some therapeutic impact of participation linked to the experience of social interaction that supported the expression and maintenance of self.

Further investigation would strengthen the evidence-base for the use of creative activities for people with dementia. In particular, an attempt to disentangle the effect of the relationship with the therapist/nurse/carer from the impact of the activity itself,

and an understanding of the longevity of any positive effects of these activities. Such findings would help nurses focus their activity, and facilitate an understanding of the impact of their interactions with patients.

### **Implications for clinical practice**

Activities that have a creative focus, such as digital storytelling, can be made available to people with dementia, and observations of the positive impact of participation suggest that this could be beneficial to them. The ability of the participants to engage, with appropriate support, with some of the more technical aspects of the process, such as the use of computers and sound recording, opens up the possibilities for people with dementia to be involved in a wide variety of projects using unfamiliar technology.

The findings suggest that people with early stage dementia are able to tell their stories within a relationship where they are offered space, time and help to develop a coherent story by the other person keeping hold of the thread. Nurses working in this way would facilitate the person with dementia's ability to participate in their care, as well as improving sense of well-being by supporting self-expression.

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